Strategic presentation on cancer rehabilitation

October 2010
Introduction

For the past decade cancer rehabilitation has been an important focus area in the national cancer plans. The reason for this is that there is growing optimism as to curing cancer, or that patients may live many years with a cancer that has been stabilized. But the course of the disease and the treatment can have some serious consequences for the patient who has cancer and who therefore is in need of physical, psychological and social rehabilitation.

Today we also know that many cancer patients develop problems and symptoms that have a negative impact on their health and possibility of resuming a work life, or participating in a normal family life after the primary treatment. These problems constitute i.a. psychological problems such as anxiety and depression, or physiological problems such as pain, sensory disorders, swelling, and a number of other problems, which are related to the particular type of cancer. Treatment of late effects is often a precondition for a successful rehabilitation.

With this strategic presentation, the Danish Cancer Society wishes to focus on how to improve the rehabilitation of cancer patients. Previous plans have been more guiding, but there is a growing need for a more concrete and goal-oriented effort in all areas of the Danish health care system. There should be increased focus on cancer patients getting their needs assessed in a much more systematic way, e.g. that they are offered a plan for rehabilitation and treatment of late effects.

The Danish Cancer Society believes that all divisions in the health care system have an obligation when it comes to identifying cancer patients’ needs for rehabilitation, and that these needs must be met with the correct measures. This implicates the need for a clearer allocation of responsibilities. It also means that hospitals should take a leading role, not only when it comes to the patients, but also when it comes to managing the technical development.

The Danish Cancer Society believes that it is time to move on, and even though there is a need for more knowledge in a number of areas, action should still be taken as matters stand at present. With this presentation, the Danish Cancer Society wishes to further the work on a Master plan for cancer rehabilitation in Denmark. Once we obtain more knowledge, we will be able to adjust the efforts in an ongoing manner. In the coming years, the Danish Cancer Society will set aside considerable amounts of money for research to ensure a continuous growth of our knowledge in this area.
Strategic presentation | the Danish Cancer Society

Frede Olesen

Chairman for the Danish Cancer Society
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Cancer rehabilitation on the political agenda

Recommendations

Political initiatives conc. cancer as the foundation for a master plan
After ten years of national cancer plans with overall recommendations in relation to cancer rehabilitation, the Danish Cancer Society finds that it is time for more specific efforts in relation to the National Cancer plan III.

Changed legislation
The Danish Cancer Society intends to request that the health legislation be changed to also include the word “rehabilitation”. This will ensure broader access to the functionalities of cancer patients seen in relation to physical, psychological and social needs. The present distinction between specialized training/rehabilitation and regular training/rehabilitation should be changed in order to not limit the hospitals’ options and obligations, when it comes to offering rehabilitation to cancer patients with special needs. Until an amendment has been made, the agreements in this field can be used as an instrument to clarify the collaboration on the rehabilitation assignment between the Danish regions (hospitals) and municipalities.

Needs assessment and rehabilitation plan
The Danish Cancer Society’s assesses that the systematic appraisal of the rehabilitation needs of all cancer patients is not in place. This applies to cancer patients in planned treatment pathways as well as the large group of cancer patients who are not enrolled in a planned treatment pathway. The Danish Cancer Society encourages everybody to systematically assess all cancer patients’ needs for rehabilitation and ensure that the time for the assessment is included in the treatment phase as well as in the follow-up phase. Based on the needs assessment, an individual plan for rehabilitation should be made. The Danish Cancer Society encourages the National Board of Health to soon secure that follow up on patients’ needs for rehabilitation and late effects are systematized for each diagnosis group. The National Board of Health should also make sure that follow-up on rehabilitation needs takes place as part of clinical controls, or as special consultations that focus on rehabilitation.
Stratified effort
The Danish Cancer Society believes that there is a need for a stratified effort similar to the Chronic Diseases Management, where the cancer patients' needs are described in relation to limited needs and late effects that require a specialized effort, and particularly complex needs for rehabilitation. The Danish Cancer Society believes it is crucial that needs are met at the right level. If the primary task is placed with the municipality, there is a risk that patients who suffer from late effects and complex needs will not be offered rehabilitation at a sufficiently high level.

Placement of responsibility
The Danish Cancer Society suggests that the regions (hospitals) to a greater extent be required to manage the professional development as well as the task of cancer rehabilitation. There is evidence that early physical activity during treatment has a positive effect, and early physiotherapy may prevent lymphodema. Hospitals report that they have had good results from rehabilitation efforts when it comes to e.g. ostomy. It should be expected that there are professional environments at the hospitals, which can take on the rehabilitation tasks provided there are sufficient resources and they have the management's attention.

The Danish Cancer Society suggests that it be part of the National Cancer Plan III that all cancer wards establish a specialized rehabilitation- and late complication ward with a view to improving the possibilities of establishing and remedying late effects for cancer patients in need of special services. At the same time, the wards can also support the professional development of the municipalities in relation to a more maintaining kind of rehabilitation.

The Danish Cancer Society is of the opinion that municipal cancer rehabilitation ought to be based on a new Danish MTV regarding the obviousness of a rehabilitation program, which consists of physical exercise and psychosocial interventions. To follow up on the rehabilitation projects run by the municipalities, the Danish Cancer Society intends to enter into dialog with the Ministry of Interior and Health, and the Association of Municipalities, in order to put cancer rehabilitation with focus on network formation and education on the agenda.

There is also a need for establishing a nationwide offer to a group of cancer patients who have particularly complex needs for rehabilitation.

The Danish Cancer Society is working to set aside 20 million Danish Kroner each year on the Finance Act of 2011. This amount will be earmarked for research and development of rehabilitation for cancer patients with special needs. The model is the Rehabilitation Center in Dallund, where
focus is on knowledge and the development of rehabilitation offers for cancer patients with complex needs.

Pathways, guidelines and programs
The Danish Cancer Society encourages the National Board of Health to set up working groups, which can draw up specific guidelines and procedure descriptions for rehabilitation for each diagnosis. The guidelines should be incorporated into the pathways, and the supply should be interdisciplinary because physical, psychological and social problems should be considered. Furthermore, the Danish Cancer Society will encourage the National Board of Health to formulate a guide on cancer rehabilitation in which the tasks assigned to the hospitals and/or the municipalities should be described in detail.

Registration of late effects and quality assurance
The Danish Cancer Society will encourage the health authorities and clinical specialist societies to systematically register the rehabilitation needs and late effects in order to identify late effects in relation to new cancer treatment regimens.

In the present documentation systems, it is not possible to assess whether the relevant identification of needs is taking place, not least in the primary sector where rehabilitating activities are not being documented at all. The Danish Cancer Society is of the opinion that the regions and municipalities should consider how the data basis for cancer rehabilitation activities in Denmark may be improved.

Research
The Danish Cancer Society has set aside significant amounts of money for research in rehabilitation and late effects. It is, however, estimated that there is a need to conduct a rather large prospective cohort study of Danish cancer patients' rehabilitation needs and late effects, where the patients should be followed over a number of years. Further to that, there is a need to conduct research into the effect of cancer rehabilitation

Development
The Danish Cancer Society suggests that a national initiative be launched, e.g. via establishing a task force that should focus solely on all the aspects of the cancer survivor’s needs. The Danish Cancer Society intends to take on the leading role.
Cancer plans and rehabilitation

The occurrence of cancer in Denmark is rising steadily. Approximately 31,000 individuals receive their first cancer diagnosis each year, and 210,000 Danes live with cancer or are cancer survivors. Fortunately, more and more people are cured or live longer with their disease. But treatment is often stressful and for some very extensive. This is why cancer patients need rehabilitation. Many patients suffer from problems and late effects following treatment, but this of course depends on the type of cancer and treatment, spread, and perhaps other already present diseases. In the years to come, more and more Danes will suffer from late effects and thus need rehabilitation.

In both National Cancer Plan I and II, and not least in the National Board of Health's relevant health professional discussion paper to National Cancer Plan III, “A strengthened effort on the cancer area”, cancer rehabilitation remains a focus area. In all three plans it is pointed out that cancer rehabilitation must be seen as an integrated part of cancer treatment, and that each cancer patient's need for rehabilitation should be assessed. Further to that, clinical guidelines and patient pathway descriptions should be developed and implemented.

The Danish Cancer Society estimates that, in spite of 10 years of planning, a clarification of the rehabilitation efforts for cancer patients in Denmark has only taken place to a limited extent. In its hearing statement to the National Board of Health's health discussion paper, the Danish Cancer Society thus pointed out that it is necessary to work out a master plan regarding cancer rehabilitation in order to map patient needs in relation to common and specialized rehabilitation, and that the coordination between regional (hospital) and municipal offers be systematized. Further to that, the Danish Cancer Society would like to see targeted rehabilitation programs for specific diagnosis groups included in the plan, same as they believe that the capacity needs should be described.

In a memorandum to the hearing statement, The Danish Cancer Society points out that fundamental data as to the extent of the rehabilitation needs and late effects as well as activity data in the hospital sector, general practice and the municipal sector, is lacking. It is therefore recommended that a better data basis is created, and that targeted research in this area be conducted. The Danish Cancer Society also points out that there is a need for specifying the purpose of specific efforts, and a need to be able to place the responsibility for identifying the patients’ needs and for initiating the specific treatments or psychological efforts that have been identified as the patient’s needs.
The Danish Cancer Society believes that it is time to move on. Even though there is an evident need for more knowledge in a number of areas, action should be taken on the existing basis. In order to further the work on a master plan for cancer rehabilitation, the Danish Cancer Society will put forward a number of proposals as to the elements of the master plan.

**What constitutes the need for cancer rehabilitation in Denmark?**

In the White paper on rehabilitation, “rehabilitation” is defined as:

> "a goal oriented, cooperative process involving a member of the public, his/her relatives and professionals over a certain period of time. The purpose of this process is to ensure that the person in question, who has, or is at risk of developing, seriously diminished physical, mental and social functions, can achieve independence and a meaningful life. Rehabilitation takes into account the person’s situation as a whole and the decisions that he/she makes, and comprises coordinated, coherent and knowledge based measures."

Since the goals for cancer rehabilitation are formulated within physical, psychological, social and to a certain extent existential dimensions, a number of various efforts ranging from medical and surgical to psychological and social including efforts as to work life, lifestyle, physical settings, technical remedies, etc., could be included. The rehabilitation effort begins when the diagnosis is given, and the reason for this is that the rehabilitation effort should be planned as soon as possible. Rehabilitation focuses on activities that generally strengthen the functional ability, e.g. physical activity. However, many cancer patients lose specific functional abilities, or suffer from the disease or treatment, and they require special rehabilitation efforts. This could for example be lymphedema (swelling of the arm) after treatment for breast cancer. The rehabilitation effort ought therefore to also include diagnostics and treatment of specific late effects, which persist and typically comprise symptoms and problems arising in connection with the treatment. But late effects such as e.g. lymphedema may not appear for months or even years after treatment.

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1 Rehabilitation in Denmark. A white paper on the rehabilitation concept. Marselisborgcentret, 2004
There is some uncertainty as to the extent of rehabilitation needs among cancer patients, but from a starting point of view everybody needs professional support in order to reestablish as normal a life as possible. While interventions in general practice and at municipality level might suffice for several patients cf. the least demanding stratum in the aforementioned risk stratification, several studies show that there is also a significant need for a specialized and risk stratified effort, and for continuous needs analyses that will help target the efforts.

A Danish survey conducted among approx. 2,000 cancer survivors headed for a rehabilitation stay at Rehabilitation Center Dallund thus showed that approx. 60% stated that they believed they were in poorer physical shape and had weaker muscle strength than others their age. ²

In the same survey, 79% of the lung cancer survivors, and 66% of the breast cancer- and colon cancer survivors stated that they suffered from fatigue. 30% of the breast cancer survivors stated lymphedema, while 63% stated hot flashes. Among prostate cancer survivors, 69% had sexual problems, and 53% had difficulty urinating.

A Danish survey has found that 47% of women who have undergone surgery for breast cancer experience pain 2-3 years after treatment, and 58% report that they experience sensory disturbances. ³

² Mette Terp Høybye. Research in Danish cancer rehabilitation: Social characteristics and late effects of cancer among participants in the FOCARE research project. Acta Oncologica, 2007
A few surveys have shed light on how the cancer patients themselves experience the need for support. A British survey has examined cancer patients' self-experienced needs for support in relation to physical, psychological, care, and other needs immediately after treatment for cancer, and again 6 months later. Right after treatment, 34% of the patients reported that they had five or more needs that had not been met. After six months, 20% still had five or more unfulfilled needs, and 11% of the patients, who only reported a few needs immediately after the treatment, had five or more needs six months after the treatment.

A Danish survey has examined the cancer patients' self-experienced needs for physical as well as psychosocial rehabilitation 15 months after they had been diagnosed with cancer. Approximately 30% of the respondents had had psychological reactions, 50% feared a relapse, 44% had nutritional problems, and 35% needed remedies or physical rehabilitation.

In a Norwegian survey of cancer patients' self-experienced conditions of life, 27% stated that they had a great need for one or more types of rehabilitation efforts, and 35% stated that they had a limited need. Approximately 60% of the patients who had stated a need for psychological counseling did not receive an offer. Late effects and rehabilitation needs which aren't met may have consequences for the patient's work life, social life, marriage, and overall quality of life. A lack of rehabilitation will not only have an economic impact on the person suffering from cancer but on society as a whole because of the diminished workforce - and thus no earnings - and an increased expenditure for the healthcare sector.

There are relatively few and uncertain estimates as to how many cancer patients in fact need rehabilitation services from the health care sector. A Dutch report estimates that approx. 25% of the cancer patients need rehabilitation. It is not evident how the Dutch have reached this conclusion. A Norwegian report states that around half of the patients have a good prognosis, and that 20% need rehabilitation while they are hospitalized. 30% need care on a daily basis whereas 10% need care on an outpatient basis. Among fatally ill patients, five percent need rehabilitation while in hospital, and 10% need care on an outpatient basis. On top of that there are the patients

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5 Mikkelsen T, Søndergaard J, Sokolowski I, Jensen A, Olesen F. Cancer survivors’ rehabilitation needs in a primary health care context. Family Practice 2009; 26:221-30
6 Kreftrammedes levevilkår. Fafo-rapport 2008:47
7 Gijssen B et al. Kanker en revalidatie. Herstel en balans een innovatief programma, 2005
who suffer from late effects. Put together, these estimates suggest that almost 50% of cancer patients need rehabilitation.  

A British report made by the National Health Service in Great Britain estimates that around 70% of cancer patients have problems that can be remedied provided these patients receive support and education from the health care sector that will enable them to deal with the problems that arise over time. 30% will develop problems that require professional help, and five percent will need a specialized, multidisciplinary effort. The British estimates form the basis of the graduated effort on page 9.

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The Danish Cancer Society's expectations of a master plan on cancer rehabilitation

Early onset rehabilitation in relation to treatment

Several recent studies have shown the importance of an early onset rehabilitation effort in relation to treatment. A Danish study has shown that six weeks of supervised training at the hospital may reduce fatigue and increase functional ability and wellbeing.\(^{10}\) On this basis, physical training is now being offered under the name “Body and cancer” at Rigshospitalet (Copenhagen) and Århus Hospital, where the training the latter place takes place at Hejmdal in cooperation with the Danish Cancer Society’s counseling team. Another study has shown that early onset rehabilitation in the form of physiotherapy to treat lymphedema immediately after surgery in women who suffer from breast cancer, and who have had lymphnodes removed during surgery, reduces the frequency of lymphedema with 70%.\(^{11}\) Danish hospitals manage the tasks of rehabilitation when it comes to several types of rehabilitation, e.g. ostomy patients and head- and throat cancer patients. On these grounds, the Danish Cancer Society expects that National Cancer Plan III will ensure that Danish cancer patients can be offered physical training while they are being treated, and that it be considered if the early treatment of lymphedema is good enough in Denmark.

The early onset rehabilitation implies that all cancer patients be continuously assessed when it comes to rehabilitation needs, and that a specific plan for rehabilitation is worked out for the patients that need it. The oncological wards and other relevant wards that treat cancer should therefore have expertise within the fields of cancer rehabilitation and late effects.

What should a rehabilitation program contain?

A new MTV has scrutinized the scientific evidence for rehabilitation efforts aimed at breast cancer, colorectal cancer and prostate cancer\(^{12}\), and the MTV recommends that patients who have been diagnosed with one of these cancer types should be offered a rehabilitation program, which includes physical exercise and psychosocial interventions. It also recommends that lymphedema treatment be carried out according to technical guidelines on women who have had breast cancer.

\(^{10}\) Adamsen et al. Effect of a multimodal high intensity exercise intervention in cancer patients undergoing chemotherapy: randomized controlled trial. BMJ 2009;339:b3410
\(^{11}\) Lacomba MT et al. Effectiveness of early physiotherapy to prevent lymphoedema after surgery for breast cancer: randomized, single blinded clinical trial. BMJ 2010; 340:b5396
\(^{12}\) Rehabilitering efter brystkræft, tyk- og endetarmskræft og prostatakæft en medicink teknologivurdering. Sundhedsstyrelsen 2010
surgery. For men who have undergone surgery for prostate cancer, pelvic floor exercises should be added to the technical guidelines. It remains unclear how great effects such interventions may have and it is necessary to conduct more scientific studies in all areas.

The rehabilitation program should also contain information as to a healthy lifestyle and relevant support when it comes to changing behavior in relation to food, smoking, physical activity and alcohol. The rehabilitation program should finally contain interventions as to specific late effects.

The MTV recommend that all patients be systematically assessed as to rehabilitation needs in connection with treatment or control, and that the outlined interventions are launched for the patients who have a need. Cancer rehabilitation is thus a task that both the hospitals and the municipalities should deal with same as general practice should play a role here, when it comes to the assessment of needs and visitation, etc.
To whom should the task be assigned: region (hospital), municipality, or general practitioner?

What are the Danish Cancer Society’s thoughts as to the placement of the rehabilitation assignment?

Rehabilitation is not a concept in the Danish health legislation. The Danish health legislation speaks solely about training and according to the law, the patient must be offered a physical training plan after he/she has been discharged from the hospital provided there are medical reasons. The Health Act also states that the municipalities must offer free-of-charge physical training to persons who, for medical reasons, require training. According to the amendment to the act, one distinguishes between two types of physical training: specialized training and ordinary training. Specialized physical training requires a contemporary or cross disciplinary training at specialist-level, which intends a very close coordination of physical training, diagnosing and treatment. “Specialized physical training” is training which, for the sake of the patient’s safety, can only be offered at the hospital. Ordinary physical training describes the non-specialized training, i.e. all other types of training.

The Danish Cancer Society believes that the present definitions in the Health Act are inexpedient. Even though the health authorities have pointed out that training is defined in broad terms which include physical, psychological and social functional abilities, the layout as to the training plans focuses – in practice - on the physical functional ability. This means that the patient’s psychosocial problems will not automatically be assessed, even though such problems are well-known. Thus, the Danish Cancer Society believes that the term “training” in the law should be replaced by the broader term “rehabilitation”. Until an amendment can be agreed upon, the health agreements may be used as an instrument for clarifying the collaboration as to the rehabilitation tasks between the regions (hospitals) and municipalities.

The division into specialized and ordinary training in the present legislation gives reason for confusion when it comes to the efforts. The quite narrow definition of “specialized training” means that the efforts to rehabilitate patients at the hospitals are indeed limited, and it further means that the municipalities have a financial incentive to take on the task of rehabilitation themselves. It remains unresolved, if the municipalities are financially obligated to pay for the physical rehabilitation at Hejmdal, which is run by staff from Århus Hospital. It would be convenient, if “specialized” in relation to training/rehabilitation adopts the same kind of relevance as that of other health sector services. Simultaneously, this will create a foundation for the hospitals to develop specialized rehabili-
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Pation programs based on professional expertise and cross-disciplinary efforts. This way, the hospitals can build expertise in the area of cancer rehabilitation while maintaining special focus on treatment of late effects in collaboration with relevant clinical specialties. Establishing special units for rehabilitation and late effects in connection with the oncological wards, and in close collaboration with the relevant surgical wards etc., is an option.

The purpose of the health care structure reform in Denmark is i.a. that larger municipalities get the opportunity of building stronger specialist environments and establishing health centers, and so forth. Status today is that there are significant problems in the municipalities when it comes to cancer rehabilitation, and that cancer rehabilitation in many municipalities has never really commenced, and offers vary greatly. There is no clear delimitation in relation to regional (hospital) and municipal tasks. There is a great need for coordinating the rehabilitation procedures, and experiences from 11 municipal cancer rehabilitation projects in 15 municipalities demonstrate that there are significant challenges in relation to visitation and coordination between the hospitals and the municipalities and the municipal administrations. Municipal health centers should frame the municipal effort.

The Danish Cancer Society suggests that the regions (hospitals) are assigned greater responsibilities when it comes to rehabilitating cancer patients and that there be more focus on the early onset of the rehabilitation effort and following treatment of late effects. The municipalities will be able to focus on rehabilitation on the basis of the evidence of physical activity and psychosocial support programs, worklife, etc. Such a division of tasks will make the division of responsibilities more evident, and it will become possible to make arrangements as to rehabilitation and treatment of late effects at the general practitioner’s office.

Model for graduation of effort

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13 Kommunal kræftrehabilitering. Erfaringsopsamling fra 11 kommuner. Syddansk Universitet 2010
Like the National Board of Health’s pathway programs for chronic illnesses, cancer rehabilitation may be described as a graduated effort, where patients can be stratified according to different needs, and where the efforts should be managed by the relevant units. 14 Cancer patients who have demarcated rehabilitation needs, and where the needs assessment determined by the hospital does not indicate complex needs nor needs for a specialized rehabilitation and treatment of late effects, may be rehabilitated within the framework of the municipalities in close collaboration with the general practitioner. Cancer patients who are in need of a specialized effort, e.g. patients who suffer from late effects, or risk developing late effects, e.g. after breast cancer, head/throat cancer, brain cancer, etc., will begin the specialized rehabilitation at the hospital that has treated them. It is not possible to state precisely - on the present grounds – how the division of cancer patients is in the stratified model. However, British estimates do suggest that the division is as stated in the model, and since the estimates are used in the NHS National Cancer Survivorship Initiative, they will be our points of reference as well.

Physical exercise and early physiotherapy during treatment is part of the specialized effort to counteract e.g. lymphedema. The Danish Cancer Society recommends that all cancer wards establish specialized rehabilitation and late effects units to improve the possibilities of assessing and remedying late effects in cancer patients who need specialized treatment. These units will also serve as

14 Forløbsprogrammer for kronisk sygdom. Sundhedsstyrelsen, 2008
a source of inspiration for the municipalities and their technical development in relation to maintaining rehabilitation after discharge.

**Any particular groups? – The broken patients**

Based upon the scientific literature, it is not possible to identify specific patient groups who are in need of intensive rehabilitation. The Danish Cancer Society is familiar with a few cases, where a longer rehabilitation stay has made a difference in restoring the patient’s functional ability. The professional environments point to several patient groups, where the disease may be particularly straining on for example patients who suffer from brain cancer, head-throat cancer, lung cancer and hematological types of cancer. In the Copenhagen region, a few cancer patients have been referred to Esbønderup Hospital for rehabilitation.

At Vejlefjord Rehabilitation Center, approximately four patients with a brain-tumor are referred each month. According to the professionals, the rehabilitation needs will increase if there is co-morbidity, high age, social problems, lack of a social network, and lifestyle-problems, etc. Municipal rehabilitation projects have identified particularly burdened cancer patients, who require a quite high level of rehabilitation due to complex and long-lasting needs for rehabilitation and a significant risk of functional disabilities in a number of important function areas, and where there is a need for a rather significant interdisciplinary effort.15

**Case**

Younger man, married, several children. Has had surgery for oral cavity cancer and received subsequent radiation- and chemotherapy. Has difficulty opening up his mouth. All teeth have been removed due to a stiff jaw. Almost no mimic. Suffers from dryness of mouth. Difficulty speaking, difficult to understand, cannot talk in a telephone. Eating problems, and cannot eat solid food. Is afraid of drooling and spilling food, and cannot eat out. Takes a long time to eat. Heavy weight loss. Severe fatigue. Poor physical condition. Difficulty acknowledging own situation. Socially withdrew because other people want to know about his situation. Unemployed because the place of employment has been closed. Has experienced a lack of coordination of efforts so far.

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Rehabilitation Center Dallund

Rehabilitation Center Dallund has sofar only received very few patients with particularly complex needs, or needs that correspond with the middle segment of the model for graduation of efforts.

The Danish Cancer Society estimates that there is a smaller group of cancer patients with a particularly complex need for rehabilitation. However, this group needs a center that can offer and perform intensive rehabilitation and that has interdisciplinary expertise, when it comes to complex rehabilitation.

The Danish Cancer Society is working politically to put Rehabilitation Center Dallund on the Finance Act from 2011 with an annual fund of 20 million DKK for the running of the center, the development and research as to rehabilitation offers for cancer patients. The center must cooperate closely with the National Research center for Cancer Rehabilitation at University of Southern Denmark same as it is intended for a role as knowledge center and teaching center for cancer rehabilitation. When the results from the negotiations regarding the Finance Act have become available, the future development of Rehabilitation Center Dallund will be discussed.

Pathway programs as the foundation for rehabilitation efforts

In accordance with the Health Board's report on Rehabilitation for cancer patients in patient pathways\(^\text{16}\), it is recommended that all cancer patients in pathways be systematically assessed as to their needs for rehabilitation. The times for assessment are placed both in the treatment-phase and in the follow-up-phase, and the assessments are relevant to hospitals and the primary sector. It is also recommended that coherent rehabilitation procedures be created via local agreements on the division of work between regions (Hospitals) and municipalities. It should be clearly stated what the region respectively the municipality is expected to handle.

In relation to the complexity of the efforts, which includes efforts across sectors, time-perspective, etc., a model for pathway-programs from other chronic diseases could be helpful, when it comes to creating coherency in the rehabilitation pathway. Rehabilitation pathways typically consist of one plan, or pathway-description, which describes the various types of interventions and the organizational framework. The pathway program can be defined as a multidisciplinary effort through the entire course of the disease across the healthcare sector. At regional level, there are guidelines as to the elaboration of pathway descriptions. Same as for other chronic diseases, it is recommended

\(^{16}\) Rehabilitering for kræftpatienter i pakkeforløb. Sundhedsstyrelsen, 28. november 2009
that a regional cancer rehabilitation coordinator be appointed to manage the overall coordination, planning and quality assurance of the entire rehabilitation offer to cancer patients in the region.  

Inspired by the rehabilitation methods applied to patients suffering from cardiac diseases, a model for cancer rehabilitation may look like this:

<table>
<thead>
<tr>
<th>Partners throughout the three phases of cancer rehabilitation</th>
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<tr>
<td><strong>Phase I</strong></td>
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<tr>
<td>Primary contact</td>
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<tr>
<td>Days/weeks</td>
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<tr>
<td>Treating ward</td>
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<td>Physiotherapy (lymphoedema)</td>
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<td>Psychologist</td>
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<td>Physical training program</td>
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<td>Patient school</td>
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<tr>
<td>The Danish Cancer Society’s counseling center</td>
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<tr>
<td>Hospital</td>
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**Visitation and documentation**

The Danish Cancer Society expects that all cancer patients be systematically assessed as to needs for rehabilitation with a view to a relevant rehabilitation offer. The different authorities must make sure that they coordinate the rehabilitation phases. In the light of experiences from rehabilitation projects on a municipal level, the Danish Cancer Society finds that the assessments of the rehabilitation needs are not systematically carried out at present. A systematic assessment can be carried out in the treatment phase, at follow-up-visits, at discharging the patient, or at the general practitioner’s office. With the present documentation system it is not possible to estimate if the re-

17 Kronisk sygdom. Patient, sundhedsvæsen og samfund. Forudsætninger for det gode forløb. Sundhedsstyrelsen, 2005
relevant needs assessment takes place, not least when it comes to the primary sector where rehabilitation activities aren’t documented.

The need for research and development

As mentioned previously, there is no doubt that there is a great need for rehabilitation, and several research projects show that rehabilitation has a significant and positive impact on the cancer patient’s work life and social life. But a number of areas reveal that there is a continuous need for research as to the effect of the mentioned interventions, and there is also a need for developing method and organization. The MTV-report on rehabilitation after breast cancer, colorectal cancer and prostate cancer states that in spite of significant international research activities within the field of rehabilitation, there is a great need for conducting large, controlled clinical studies that can shed light on the effects of targeted rehabilitation programs for specific target groups. It is necessary to test the intervention on groups with well-defined rehabilitation needs. In relation to the target group, there is also a need to distinguish between the two sexes same as there is a need to include a social perspective and consider other chronical diseases that the patient may be suffering from.

In collaboration with Novo Nordisk Foundation, the Danish Cancer Society has launched a strategic initiative concerning research in rehabilitation for patients with cancer, or after cancer: “Back to everyday life – Optimized rehabilitation of cancer patients.” The initiative focuses on the rehabilitation needs seen from the patient’s perspective, and the point of departure is the patient’s everyday life. Thoroughly described interventions that shed light on the effects of rehabilitation programs aimed at specific target groups of cancer patients will be tested. The initiative will consider which methods and tools are preferred when it comes to organization and implementation.

The research themes have been announced after the Danish Cancer Society and the Novo Nordisk Foundation in September 2009 had invited a number of experts to a workshop. At present, 30 million DKK have been offered to the research syndicate that will accept the assignment. At present, a panel of international experts is reviewing the incoming proposals as to research programs, and the winner will be announced at the end of 2010.

The Danish Cancer Society has entered into an agreement with the University of Southern Denmark to sponsor the establishment of a National Research Center for Cancer Rehabilitation with the amount of 2.5 million DKK per year over at five year period at the Institute for Public Health at the University of Southern Denmark. The center was established in 2009 and has a center manager, a professor on part-time and more senior researchers and PhD-students.
The Danish Cancer Society has granted 7.5 million DKK from the strategic funds to research in late effects, and a professorship in late effects has been announced.

The Danish Cancer Society works politically to further develop and test new cancer rehabilitation offers at Rehabilitation Center Dallund, and from 2011 it is expected that twenty million DKK will be set aside on the Finance Act and earmarked for research and development of rehabilitation offers for cancer patients. The research will be planned in collaboration with the University of Southern Denmark, the Danish Cancer Society, the regions and municipalities, and the general practitioners.

The Danish Cancer Society estimates that there is a need to set aside resources over a five-year period in order to complete a large prospective cohort study of Danish cancer patients’ rehabilitation needs, and late effects in a time perspective. There is also a need for conducting research as to the effects of cancer rehabilitation.

Several countries have taken initiative to outline recommendations concerning the course for cancer patients, e.g. rehabilitation. In The Netherlands they have developed evidence based guidelines concerning cancer survivors for professionals, and in the USA the Institute of Medicine worked out the report “From Cancer Patient to Cancer Survivor: Lost in Transition”. In England, the cancer foundation, Macmillan, and the Department of Health have outlined an initiative called “the National Cancer Survivorship Initiative”.

The Danish Cancer Society suggests that a national initiative be launched, e.g. via the establishment of a task force, which will focus on all the aspects of the cancer survivor’s needs. The Danish Cancer Society intends to take on the leading role.

Approved by the Executive Committee of the Danish Cancer Society
15. September 2010